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ABSTRACT

Presented is the final report of the ad hoc consultant group established to examine the advisability of NIMH (National Institute of Mental Health) making an explicit policy decision to reenter the field of mental retardation, to advise the two institutes (NIMH and NICHD--National Institute of Child Health and Human Development) regarding possible divisions of responsibility, and to indicate potential areas for cooperation and shared responsibility. An introductory section reviews the scope of the problem and recommendations regarding research priorities, funding for research and training, and changes within the two institutes. Considered in Section II are the range of federal effort in mental retardation, background information on NIMH and NICHD, and involvement of university affiliated facilities and nonfederal organizations in the field. A third section focuses on the etiology of mental retardation, the most serious knowledge gaps that remain with respect to prevention, and other priority research areas. In a final section, current activity of and recommendations for NICHD with regard to mental retardation are discussed; ways in which NIMH and NICHD might complement one another's strengths are considered; and a priority list of mental retardation activities is given. (SBH)

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FEDERAL RESEARCH ACTIVITY IN MENTAL RETARDATION:

A REVIEW WITH RECOMMENDATIONS FOR THE FUTURE

U.S. DEPARTMENT OF HEALTH,
EDUCATION & WELFARE
NATIONAL INSTITUTE OF
EDUCATION

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Report of the Ad Hoc Consultants on Mental Retardation

To the Directors
National Institute of Child Health and Human Development
National Institutes of Health
and the
National Institute of Mental Health
Alcohol, Drug Abuse, and Mental Health Administration
of the
Department of Health, Education, and Welfare

February 1977

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Foreword

More than 6 million Americans are mentally retarded to some degree; between 1 and 2 million are profoundly handicapped. It costs more than \$5 billion each year to provide such individuals with special care and education. The social costs are even greater. To lessen this impact, the myriad causes of mental retardation must be fully understood and means found for preventing the disorder. Where prevention is not yet possible, amelioration is the goal.

Progress toward these goals has been made by a number of private and government organizations, including the National Institute of Mental Health (NIMH) and the National Institute of Child Health and Human Development (NICHD).

The NIMH has been actively involved in fundamental mental retardation research since the 1950's, when Congress allocated specific resources for research and training in mental retardation. This appropriation marked mental retardation as one of the main priorities of the NIMH. Support of mental retardation research at the NIMH reached its peak in 1964. With the creation of the NICHD, the NIMH research budget in mental retardation decreased considerably.

Mental retardation has been a major research interest of the NICHD since the Institute was founded in 1963. On signing the Act that established the Institute, President John F. Kennedy cited prevention of mental retardation as a major goal of the new Institute:

"This legislation...should permit major advances in the conquest of those chronic conditions such as mental retardation...which derive from aberrations in early development..."

Today, the NICHD is the primary locus in the Federal government for mental retardation research; the Institute supports 12 mental retardation research centers across the country and numerous projects in other institutions.

To continue our progress in understanding and preventing mental retardation and alleviating its effects, Federal and private agencies interested in the problem must work together and plan well ahead. We believe the report and recommendations that follow will provide a useful reference for planning future research and national service delivery policy. That is why the NICHD and the NIMH decided to print and distribute this report to the mental retardation research and planning community.

With continued support, thoughtful planning, and interagency cooperation, we should be able to accelerate progress against mental retardation, thereby improving the quality of life for all Americans.

Norman Kretchmer, M.D., Ph.D.
Director
National Institute of Child Health
and Human Development

Bertram S. Brown, M.D.
Director
National Institute of Mental Health

PREFACE

In May 1975, the Directors of the National Institute of Child Health and Human Development (NICHD) and the National Institute of Mental Health (NIMH) jointly convened this group of six Ad Hoc Consultants on Mental Retardation. We were requested, in light of the history of the past ten years and in the context of the needs of the field, to examine the advisability of NIMH making an explicit policy decision to reenter the field of mental retardation; to advise the two Institutes regarding possible divisions of responsibility; and to indicate potential areas for cooperation and shared responsibility.

The letter of invitation said, in part:

We are deeply interested in facilitating the development of all dimensions of the mental retardation research field. This interest extends to contributing, through research activities and information dissemination, to the improvement of the health, mental health and social functioning of the retarded and their families

For the purpose of this study we assure you full access to the information and staffs of both our Institutes. The cost of this study will be supported jointly by the two Institutes. Staff support will also be jointly provided.

This is the final report of the ad hoc consultant group. We have heard detailed presentations from the staffs of both Institutes. We have examined voluminous documentation with respect to the mental retardation field, and with respect to the organization of the federal effort in general and of the two Institutes in particular. (A list of the material we reviewed appears in the Appendix.) We met for six two-day meetings: June 20-21, July 17-18, October 9-10, December 15-16, 1975; February 2-3 and May 19-20, 1976, and discussed our report following these meetings.

Mental retardation is a major social problem in America today. We hope, therefore, that the two Institute Directors will see that our report is widely read by all those concerned with prevention and amelioration--experts in the field, and policy makers and the public as well. With this in mind, we have decided to produce a nontechnical document.

We would like to express our thanks to the two Directors, Dr. Norman Kretchmer of the NICHD and Dr. Bertram Brown of the NIMH, for their vision in recognizing the need to cooperate on this important problem. We also thank the staffs of both Institutes for their help in furnishing us with the materials we needed. Finally, a special note of thanks must be given to Ms. Felicity Skidmore, our writing consultant, for her extraordinary efforts in synthesizing, consolidating and editing the enormous bulk of material that was used in the various stages of draft and final preparation of this report.

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INTRODUCTION AND MAJOR RECOMMENDATIONS

Scope of the Problem

Estimates of the number of mentally retarded persons in the United States range upward from two million to six million. It is in itself an important comment on the state of knowledge in this area that we cannot make a precise estimate. Even the conservative estimate, however, shows it to be a substantial social problem--at least one in every hundred Americans is a victim of mental retardation.

Mental retardation is a syndrome, commonly identified by the presence of several signs: a significant impairment in intellectual performance (usually measured as having an IQ of 70 or below); a concurrent impairment in general adaptation; and the appearance of these impairments before the age of eighteen (the attainment of mental maturity).

Many causes have been identified. But in only about 25 percent of the cases can any definitive biomedical etiologic factors and clinically identifiable somatic impairments be found. Further complicating the picture is that those cases with identifiable somatic impairments are distributed evenly throughout the socioeconomic scale. The 75 percent of cases without such physical signs show, in contrast, a correlation between the proportion of mentally retarded and socioeconomic status.

Roughly six million of the population have IQs of 70 or below. The reason for uncertainty as to the incidence of mental retardation stems from

the fact that only a subset of these also has impaired social adaptation. A commonly cited figure is that one-third of these show maladaptive behavior. Accurate statistics are still impossible, however, because the measures of adaptive behavior generally in use have been standardized on institutional populations and are inadequate for general prevalence studies. Further, since cognitive achievement is perhaps the major social demand of our society during the school years, many children with IQs at 70 or below are likely to be diagnosed as retarded between the ages of 6 and 18 for that reason alone—only to disappear from the category after school years because their adult adaptation appears satisfactory.

It is clear from this brief description that there is much we still don't know about mental retardation, with regard to both its etiology and its measurement. It is also clear that for further headway to be made the contributions of many disciplines and professions are needed. The traditional fields of medicine and the natural sciences will not solve the puzzles of mental retardation without the research efforts of the behavioral, biobehavioral, and psychometric sciences.

Current Government Activity

Current expenditures on behalf of the mentally retarded from all public sources are in the neighborhood of \$5 billion a year. Public funds going to support research related to mental retardation constitute less than 1.5 percent of total expenditures. This proportion going to research is very low compared to the 5 percent of expenditures associated with research and development in private industry.

The major mental retardation programs at the federal level are in the Department of Health, Education, and Welfare (DHEW).^{*} They are not, however, under one Assistant Secretary, but spread across all five divisions—Health, Human Development, Education, the Social and Rehabilitation Service, and the Social Security Administration.

The National Institute of Child Health and Human Development, NICHD (under the Assistant Secretary of Health) has been designated the lead federal agency for mental retardation research since 1963, and funds most of the research in mental retardation. The major federal service components are, however, housed in the Social and Rehabilitation Service, the Office of Human Development, and the Office of Education. The National Institute of Mental Health (NIMH), in contrast, had a significant role in federal activity in the mental retardation area in the 1950s and early 1960s; its current involvement in mental retardation research is very small and its mental retardation service component is minimal.

Coordination of the federal effort in mental retardation has always presented problems, as this report will go on to describe. In 1972, the President's Committee on Mental Retardation made the following plea:

Coordination is probably the most crucial factor in successful administration of mental retardation programs. This is so because mental retardation cannot be confined to any one health, education, rehabilitation or welfare program or any single disciplinary group. A total program must include a wide range of activities designed to confront the problem of mental retardation simultaneously from many vantage points.

In 1976, the Office for Handicapped Individuals—currently charged with coordinating information and resources and operating as a clearinghouse for the entire physically and mentally disabled population—found itself forced to repeat the identical statement.

^{*} The Department of Health, Education, and Welfare was reorganized, effective March 1977, subsequent to preparation of this document.

The mental retardation area is clearly not alone in its lack of coordination. Coordination is constantly cited as a problem in numerous areas of government activity, and we certainly do not underestimate the difficulties.

We do, therefore, wish to applaud in the strongest terms the initiatives on the part of the Directors of NICHD and NIMH in asking us (1) to examine what the objectives of both Institutes should be in this area, and (2) to help them relate the work of each Institute to that of the other in order to be more effective. We also applaud the extent to which they are encouraging communication across these institutional boundaries, not only at the directoral level, but at all staff levels.

It is unusual in government that two Institutes--not even within the same agency--show this willingness and ability to cooperate. It is a particularly hopeful sign for such an important social area as the health needs and problems of a large and acutely vulnerable group of Americans--the mentally retarded and their families.

Summary of Findings and Recommendations

Research Priorities

The etiology of mental retardation is still largely unknown. Almost nothing is known about the majority of cases of mental retardation that are attributed (1) to environmental somatic factors during the prenatal, perinatal, and postnatal period, and (2) to the effects of early childhood experiences. Their etiologies are still major mysteries. Since three-quarters of the total incidence of mental retardation is currently attributed to such causes, the high priority areas for research must lie here.

The neurosciences may yield important breakthroughs with respect to somatic injury. The behavioral sciences can be expected to yield significant etiological insights regarding both somatic injury and early childhood experience.

Fundamental behavioral and biobehavioral research on the developing nervous system should be important in discovering how somatic injury and early experience produce the syndrome of mental retardation. The behavioral sciences have much to contribute to the prevention of mental retardation, not simply to its amelioration.

There is important research to be done on the relationships of mental retardation to many specific developmental and behavioral problems (autism, child abuse, the incidence of accidents, and delinquency are examples). These issues are listed in detail at the end of the report.

The dichotomy between basic and applied research, in this as in other areas, is a false one. Fundamental advances in knowledge come from the general to the particular and vice versa.

High priority should be given to developing demographic information on the mentally retarded. We do not know to what extent mental retardation is being reduced by contraception use, steadily on the increase, and the choice of abortion by some high-risk parents after genetic counseling or amniocentesis. We also do not know whether or how the mentally retarded population is being increased by the current success of intensive care units in salvaging low-weight babies. Lifespan studies of the mentally retarded must be undertaken because little is known about the life pattern of the retarded, particularly those who are not institutionalized. We do not even know their life expectancy.

High priority should be given to studying the mentally retarded and their environments. The mentally retarded have been studied for too long in isolation. The mentally retarded child must, for example, be studied in relation to the family--whether it be natural parents, foster care, substitute or supplementary parental care. The impact of recent drives toward deinstitutionalization and "mainstreaming" must also be studied more intensively and more systematically.* Public policy is now spending many millions on mainstreaming. Systematic research on its effects and an examination of its impacts at a service level are mandatory if the retarded are not to be the victims of a policy designed for their benefit.

Transformation of research findings into usable form by practitioners and by the public needs greater effort. There are currently no incentives (professional or financial) for researchers to put their findings into a form that can be used either by practitioners who work with the retarded or by the public, particularly the families of the retarded. Neither are there incentives for practitioners and service workers to make an effort to familiarize themselves with the latest research. The incentives for the families of the retarded are obvious--but they make those families very vulnerable to current "fads," which are, indeed, packaged to be persuasive.

The Federal Government needs an entity, equivalent to the Food and Drug Administration, which can protect individuals from cures that are untested or, worse, proven valueless.

Funding for Research and Training

Currently, the Federal Government is spending more than \$1.5 billion on services and income maintenance explicitly earmarked for the retarded. The states are spending many millions in addition. The public research effort is less than 1.5 percent of the total public expenditures. The training effort is of the same relative magnitude. Bearing in mind how much we still need to discover about mental retardation, we find this proportion small.

There is enough high priority research, with potentially valuable yield, for us to recommend in the strongest terms that more federal money be appropriated for research related to mental retardation, including investigator-initiated research on normal growth and development. This is not an area where so little is known that good research hypotheses are hard to formulate and test.

* Mainstreaming means making every effort to produce for the retarded a situation as normal as possible in every aspect of their lives--educational, residential, and social.

No funds should be shifted from NICHD to NIMH, nor from NIMH to NICHD. The research funds for mental retardation research are being well-utilized at NICHD. Also, current staffing constraints at NIMH are such that unless new staff is hired with interest in the mental retardation area, NIMH will find it hard to handle any additional mental retardation research.

Interdisciplinary training, despite its well-known hazards, is mandatory for such a multifaceted social problem as mental retardation--not only for perceptive research but also for sound policy formulation. Having a single discipline at one's disposal blinds one to the downside risk of any hypothesis or action.

Research training has to be a federal responsibility. First, outstanding researchers are as mobile as any group. States cannot be expected to invest in the training of people who may well leave. Second, research is generally agreed to be a federal responsibility. Manpower planning for it must be at the same level of decision making.

Federal funds for institutional research training grants in mental retardation should certainly not be further curtailed. Further cuts will lead to discontinuity in the pipeline and the real possibility of a dearth of trained researchers ten years hence. Attracting good people is a long-term process that demands funding stability. New funds after a substantial gap in funding will attract new manpower, but the quickest to move are rarely the most outstanding researchers.

There is scattered evidence that current funding levels for research training are inadequate. There is no decline in the placement of graduates from the interdisciplinary training programs, even in this period of generally declining markets for researchers. And the number of people knowledgeable about mental retardation is insufficient to fill the mid-level and leadership roles in state systems and elsewhere.

National Institute of Child Health and Human Development (NICHD)

The national focus for mental retardation research is now the Mental Retardation Branch of NICHD.* Historically speaking, the problem of mental retardation was the major reason for the establishment of NICHD. NICHD has a national responsibility to maintain its commitment of mental retardation research.

* The name of the Mental Retardation Branch was changed to Mental Retardation and Developmental Disabilities Branch subsequent to preparation of this report.

The magnitude of the social problems and the host of research issues that have not yet been addressed provide convincing evidence that mental retardation is not an area where reduced or even constant funding is called for.

Sufficient evidence was not available to make a judgment about whether the relative funding levels of the branches at NICHD were appropriate. We found no evidence of gross imbalance, but we see a need for the Director to begin to collect on a continuing basis evaluative information of many kinds and from many sources, to enable him to detect any imbalances as they occur. (Examples of the different kinds of evaluation criteria we recommend appear in the body of the report.)

On the basis of the evidence available to us, we found the research within the Mental Retardation Research Centers (MRRC) to be of the same quality as research pursued external to the MRRCs. Again, the evidence available is not sufficient to make more than tentative judgments. We recommend that the Director set up an ongoing evaluation of the quality of research conducted within the MRRCs relative to the quality of other research in the mental retardation area.

We endorse the concept of the core grant to the MRRCs for two reasons. First, the universities made a twenty-year commitment and we feel government should make one in return. Second, the core grant will help ensure funding stability for long-term large interdisciplinary research projects--essential for successful resolution of many research issues.

We recommend that NICHD continue to support program project grants even though we fully recognize that program projects are large and that our recommendation reduces the funds available for the smaller scale study and the beginning investigator.

The MRRCs should be urged to develop close cooperation with the University Affiliated Facilities (UAFs), particularly in the ten instances where both an MRRC and a UAF are located in the same university setting. Such collaboration could significantly expedite the translation of research findings into service, and focus on clinical problems in need of solution through basic research.

There has been considerable subjective concern expressed that the behavioral sciences are being squeezed in the budgetary allocations at NICHD. We have ascertained that the proportion going to the behavioral sciences has had a small overall decline since the peak year, 1968. This is due in part to changes in the budgetary allocations among branches over time. The Pregnancy and Infancy Branch has grown rapidly but the proportion of its funds going to behavioral research has remained less than 1.5 percent, and we urge sustained efforts to increase support of behavioral research concerned with early development.

There is also concern because the proportions going to behavioral research have declined about 8 percent in the Growth and Development Branch* and the Mental Retardation Branch. These branches have provided the major support of fundamental behavioral research on human development, and continued support is vital.

Our programmatic analysis leads us to observe (1) that communication among disciplines and branches should be facilitated at the top levels of the Institute; and (2) that, in order to carry through behavioral science programs well, care must be taken to ensure appropriate staffing.

One percent evaluation funds should be sought (1) to follow up graduates of interdisciplinary training programs and to assess the continuing market for such graduates; (2) to evaluate, on a wide set of criteria, the appropriateness of the current funding allocations, by discipline and by Branch, within NICHD.

National Institute of Mental Health

We strongly recommend that NIMH increase substantially the scale of its involvement in the field of mental retardation--research, training, and service. The NIMH stance since the early sixties of neglecting mental retardation constitutes discriminatory behavior against the mentally retarded. The mentally retarded have mental health needs, like other segments of the population. There are also many research issues in which mental health and mental deficits overlap.

Additional funds must be secured before NIMH can reenter the field in the way we recommend. We do not recommend efforts to find additional mental retardation funds within the existing NIMH budget because we see no existing types of expenditures that could responsibly be reduced.

As initial steps in the process of reentering the mental retardation field, the Director of NIMH should make two staffing appointments. First, he should designate a senior person in his Institute to take responsibility for implementing our recommendations. Second, he should appoint a person at the program level whose substantive interest and expertise lie in mental retardation. If hiring restrictions prohibit new appointments, a possible avenue would be to appoint a university-based researcher to a two-year position while on university leave.

* Subsequent to this report, the Growth and Development Branch was split into two branches, the Human Learning and Behavior Branch and the Developmental Biology and Nutrition Branch.

The Director of NIMH should also convene an intramural group to develop a plan of action for NIMH with respect to mental retardation. Then he should submit this plan to a public (consumer) group for review.

The service personnel in the Community Mental Health Centers (CMHCs) must immediately have mental retardation reintroduced into their training. This is a service network throughout the country through which two million adults and half a million children pass each year. Yet, during the past decade's relative neglect of mental retardation by NIMH, the system has been producing personnel with little or no knowledge of mental retardation.

NICHD/NIMH Cooperation

We applaud the unique initiative of both Institute Directors in searching for ways in which their Institutes might cooperate in order to solve more effectively the major social problem of mental retardation.

We also wish to point out that certain issues related to mental retardation are also within the mandates of other federal agencies. In our detailed recommendations we mention specific areas in which the cooperation of some third agency--examples are the Office of Developmental Disabilities, the Bureau of Education of the Handicapped, the Office of Child Development, and the National Institute of Neurological and Communicative Diseases and Stroke--is necessary for any lasting solution.

Two overarching criteria should be used, in our judgment, to determine areas for cooperation between NICHD and NIMH: (1) In what respects are the Institutes more effective working together than they are separately? (2) Where do they complement one another's strengths and weaknesses? These criteria led us to the following general assessments: NICHD is totally a research Institute; NIMH combines research, training, and service. NICHD is stronger in the natural sciences; NIMH in the behavioral sciences. NICHD sees its mandate as infancy and childhood in the traditional sense; NIMH includes children, youth, and adults within its focus. NIMH has a network of Community Mental Health Centers that needs the expertise in mental retardation of NICHD in order to meet its moral commitment to provide decent diagnostic services to all its clients and to provide effective services to its mentally retarded clients. Ten of the Mental Retardation Research Centers have ties with University Affiliated Facilities which need to be strengthened; the experience of NIMH in training service workers and incorporating research information into a treatment setting should be tapped for this purpose.

With regard to specific research topics, our judgment is that, due to NIMH's lack of involvement over the past ten years, we cannot isolate specific topics as strictly for NIMH. We have, however, included a long list of important issues as possibilities for NICHD/NIMH cooperation.

II

FEDERAL AND NONFEDERAL ACTIVITY IN MENTAL RETARDATION

The two Institutes that are the specific focus of this report, NICHD and NIMH, are both part of the Public Health Service, under the HEW Assistant Secretary for Health. Table 1 shows the comparative scale of their research-related budgets for Fiscal Year 1977. As is readily seen, research-related activities make up the entire NICHD budget, but only slightly less than one-fourth of the budget of NIMH.

TABLE 1

ROUGH COMPARISON OF RESEARCH BUDGETS, NICHD AND NIMH, FY 1977
(\$ thousands)

	NICHD	NIMH
Extramural	\$121,165	\$72,182
Intramural	14,545	13,685
Epidemiology	679	2,300
Total Research	136,389	88,167
Overhead & Other Operations	9,154	9,851
Total Institute Budget	\$145,543	\$453,432*

*The Total Institute Research Budget for NIMH is figured as \$98,018. If research scientist development and hospital improvement projects (which total \$8,890) are added, this figure becomes \$106,908.

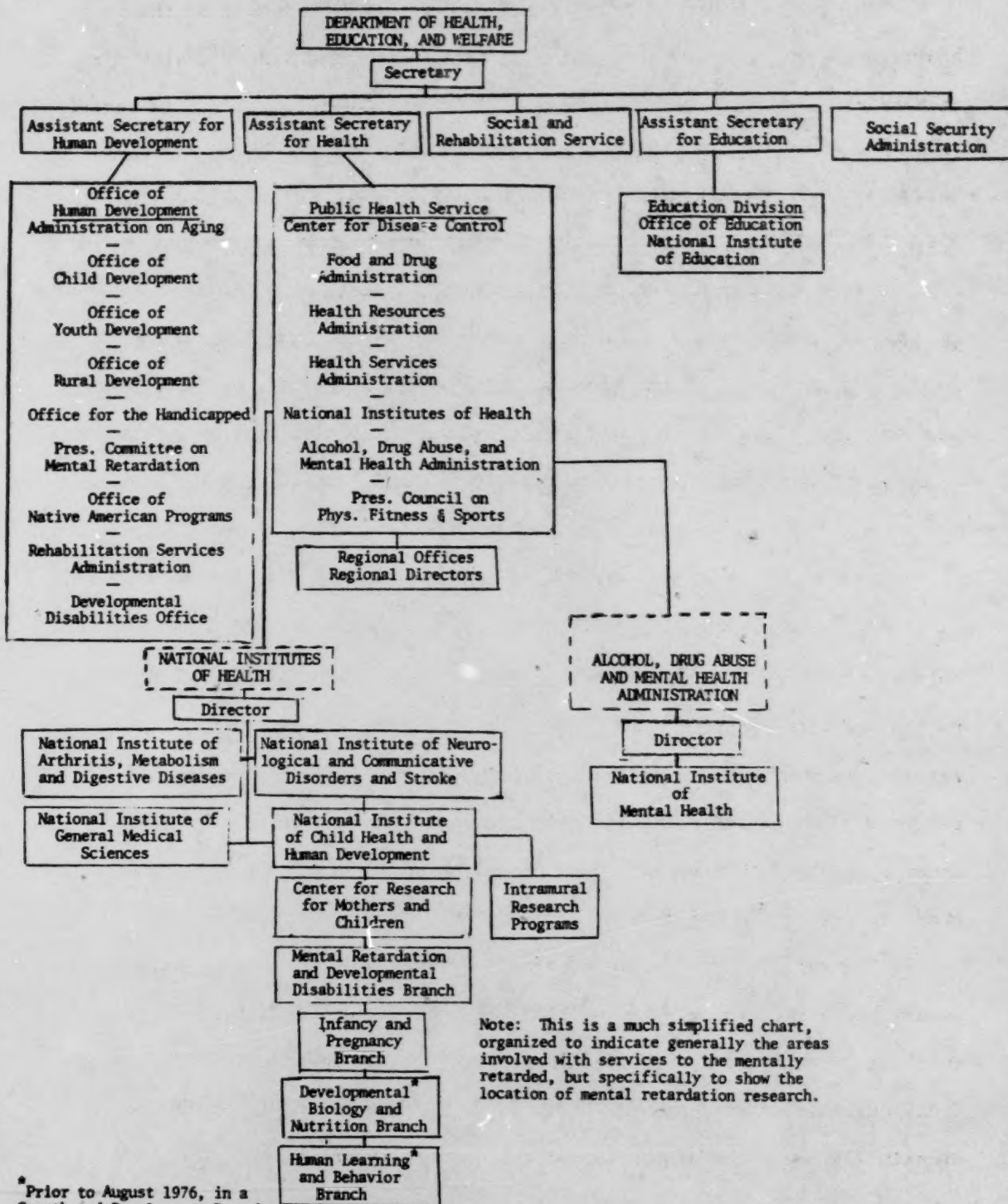
The National Institute of Mental Health (NIMH), now one of the constituent institutes of the Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA), was the site of the first federal activity in mental retardation--starting to support mental retardation research in the early 1950s. Its involvement increased, with respect not only to research but to training and service as well, throughout the 1950s. The establishment of the National Institute of Child Health and Human Development (NICHD) in 1963 within the National Institutes of Health (NIH), however, led to an administrative decision within NIMH to withdraw from the mental retardation research area. And, as the 1960s wore on, its service and training programs in mental retardation also were transferred elsewhere in HEW.

Range of Federal Effort in Mental Retardation

The two Institutes within our specific charge are by no means the only parts of the Federal Government with program responsibilities relevant to the mentally retarded. All federal activity, of course, touches the retarded in some way, as it touches all Americans. Even the programs explicitly designed for the mentally retarded, however, are by no means under a single authority--although the major ones can all be found somewhere in HEW.

Figure 1 is a selectively organized chart of HEW, showing under the Assistant Secretary for Human Development, the Office of Child Development (with Head Start and the Children's Bureau), the Office for Handicapped Individuals, the Developmental Disabilities Office (which includes responsibility for a major portion of the University Affiliated

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE ^{1/}



Note: This is a much simplified chart, organized to indicate generally the areas involved with services to the mentally retarded, but specifically to show the location of mental retardation research.

* Prior to August 1976, in a Growth and Development Branch which no longer exists.

FIGURE 1

^{1/}DHEW was reorganized in July 1977.

Facilities), the President's Committee on Mental Retardation, and the Rehabilitation Services Administration. The Public Health Service is under the Assistant Secretary for Health, and includes the National Institutes of Health, two of whose institutes are of particular interest to us here: NICHD and the National Institute of Neurological and Communicative Diseases and Stroke. The NICHD Mental Retardation and Developmental Disabilities Branch, which includes the Mental Retardation Research Centers, is of course one of the two areas of special focus. The other, which is the National Institute of Mental Health, is part of the Alcohol, Drug Abuse, and Mental Health Administration, which is also included in the Public Health Administration under the Assistant Secretary for Health. The Social and Rehabilitation Service administers over \$500 million a year in services to the retarded. The Assistant Secretary for Education has under his responsibility the Bureau of Education for the Handicapped, which supports six Research and Development Centers. The Social Security Administration administers over \$900 million a year in income maintenance and health insurance payments for the retarded.

Coordination of all this effort has remained elusive, as illustrated by the following groups (in chronological order) formed for coordination:

- 1955 HEW Secretary's Committee on Mental Retardation is established
- 1961 Presidential Panel on Mental Retardation is appointed to
prepare national plan to combat mental retardation
- 1962 Panel report supports the importance of coordination at
national and local levels, and of the HEW Committee to advise
the Secretary on activities related to mental retardation

- 1963 The Secretary's Committee on Mental Retardation is strengthened
- 1966 President's Committee on Mental Retardation is established by Executive Order
- 1968 The Secretary's Committee on Mental Retardation membership is reconstituted to include top-level executives, with the Under Secretary as chairman. Regional office staffs are assigned to coordinate their mental retardation activities
- 1970 National Advisory Council on Services for the Developmentally Disabled is formed, composed of members who were not full-time employees of the government
- 1972 The HEW Secretary establishes an Office of Mental Retardation Coordination, replacing the Secretary's Committee on Mental Retardation, to act also as liaison with the President's Committee on Mental Retardation
- 1974 The HEW Secretary establishes the Office for the Handicapped (same year renamed Office for Handicapped Individuals), incorporating the Office of Mental Retardation Coordination and headed by the former Director of that office. Office for Handicapped Individuals organizes an interagency committee of representatives of all programs for the handicapped, including the mentally retarded
- 1975 National Advisory Council on Services and Facilities for the Developmentally Disabled has its membership expanded to include nine ex officio members from HEW

1976 The President's Committee on Mental Retardation sets up an Intradepartmental Committee on Mental Retardation to develop a strategy for coordination and to get a commitment out of every HEW agency involved with mental retardation.

The Office for Handicapped Individuals is charged with coordinating information and resources and operating as a clearinghouse for the entire physically and mentally disabled population. This office, by making services received more effective and better coordinated, can only encourage coordination and cooperative planning. The President's Committee on Mental Retardation is assigned to track the national effort to combat mental retardation. It has been stated that, in coordinating prevention efforts, the Committee keeps in close touch with the National Institute of Child Health and Human Development, other NIH Institutes, the Developmental Disabilities Office, and other government as well as private agencies. At state and local levels, as well as federal, the Committee sees its primary mission as improving services and understanding and publicizing preventive measures. The President's Committee on Mental Retardation is, however, a political not an operational body. Their coordination efforts appear to be loose, though not entirely lacking.

History of NIMH Involvement

In 1956, Congress appropriated to NIMH \$250,000 for research and training in mental retardation. This appropriation was apparently the milestone that marked mental retardation as an NIMH priority. Mental retardation continued to be an NIMH priority through the early 1960s, with

the support level for mental retardation research in 1961 reaching 9 percent of the total research grants awarded.

In addition to research in mental retardation, NIMH also supported service projects. It spent nearly \$5 million on mental retardation services between 1958 and 1962. In 1964, the NIMH Hospital Improvement and In-service Training programs were established, providing mechanism at the Institute for funding projects related to mental retardation. NIMH total support of mental retardation activities reached a peak in 1966, with more than \$11.5 million obligated for a combination of research, hospital improvement, training, and hospital staff development grants.

By 1966, however, support for mental retardation research at NIMH had already declined, with some of its developmental research funding being transferred to NICHD upon its establishment. In 1967, NIMH activity in the area was further reduced by a reorganization within the Department of Health, Education, and Welfare (HEW) which consolidated all mental retardation service and service programs under the Social and Rehabilitation Service (SRS). At that time, funding for mental retardation and hospital improvement grants shifted to SRS; and over the next several years the unified effort headed by SRS absorbed practically all the other NIMH mental retardation programs in the areas of demonstration, in-service training, and basic research in child development.

Currently, NIMH activity in mental retardation is restricted to a small research portfolio of less than \$2 million. Virtually no attention is paid to mental retardation in its extensive national network of service

centers--the Community Mental Health Centers--that serve two million people a year, half a million of whom are children. Table 2 shows a breakdown for Fiscal Year 1977 of the NIMH budget appropriation.

TABLE 2

NIMH 1977 BUDGET APPROPRIATION
(\$ thousands)

	Appropriation
Research	
Grants	
Behavioral science	\$ 15,228
Clinical research	14,853
Applied research	5,975
Epidemiology	2,300
Psychopharmacology	11,885
Other (services, crime, rape, etc.)	22,671
<u>Grant Subtotal</u>	72,912
Contracts	1,570
Direct operations	23,536
Research scientist development	3,990
Hospital improvement projects	4,900
<u>Research Subtotal</u>	106,908
Training	86,149
Community programs	231,873
Management and information	<u>28,502</u>
Grand Total	\$453,432

Establishment of NICHD

John F. Kennedy's Task Force on Health and Social Security, formed in November 1960 immediately after his election, released its report in January 1961--specifically citing "the burden on family and community resources for the care of the mentally retarded," and recommending the establishment of a new National Institute of Child Health--an Institute not to be disease-oriented, but to focus on the whole process of human development. Less than one month later, President Kennedy's first Health Message to Congress recommended the establishment of the National Institute of Child Health and Human Development (NICHD) within the National Institutes of Health, citing statistics on mental retardation as having contributed to the decision to establish within NICHD a Center for Research in Child Health.

NICHD has now grown into an Institute focussed on four programs--Population and Reproduction, Pregnancy and Infancy, Developmental Biology and Nutrition, and Mental Retardation and Developmental Disabilities. The first constitutes the Center for Population Research, the other three are constituent parts of the Center for Research for Mothers and Children. Table 3 shows the relative funding of the four programs over the period between Fiscal Year 1964 and Fiscal Year 1976.

Mental Retardation Research Centers

The first recommendation of the 1962 report of the President's Panel on Mental Retardation, appointed to prepare "a national plan to combat mental retardation," was to support the action of the Congress

TABLE 3

NICHD GRANT AND CONTRACT FUNDS, BY BRANCH, FY 1964-1976
(\$ millions)

	Population and Reproduction		Pregnancy and Infancy		Growth and Development		Mental Retardation & Dev't'l Disab.	
	Grants	Contracts	Grants	Contracts	Grants	Contracts	Grants	Contracts
1964	3.27	.05	7.90	.05	9.74	.02	3.02	--
1965	4.84	.47	9.65	.13	13.27	.41	3.57	.12
1966	6.17	.15	12.55	.03	17.04	.67	4.94	.03
1967	6.77	1.21	13.63	.11	18.12	.89	5.88	.21
1968	7.93	.73	13.29	.07	17.52	1.17	6.76	.10
1969	8.63	3.27	13.43	.12	15.59	.87	8.14	.39
1970	10.53	6.86	11.74	.07	15.16	.58	9.95	.09
1971	13.40	13.00	12.04	.39	15.80	1.17	12.70	1.32
1972	20.34	15.42	13.55	.51	15.71	1.19	16.41	2.32
1973	20.05	14.60	12.94	1.15	13.75	.95	16.04	1.56
1974	30.07	15.48	18.52	1.82	19.15	1.14	18.24	1.97
1975	30.05	14.55	19.89	2.36	18.46	1.04	19.45	.96
1976	32.96	13.98	21.70	1.95	19.97	1.31	20.50	1.51

Excludes scientific evaluation grants.

to establish NICHD. Its third recommendation was "that high priority should be given to developing research centers on mental retardation at strategically located universities and at institutions for the retarded." Immediately following the release of the Panel's report, President Kennedy signed into law the legislation establishing the NICHD. Three-and-a-half months later, during the first week of February 1963, the Department of Health, Education, and Welfare formally announced the

administrative establishment of NICHD, and the President's Message on Mental Retardation called for the implementation of the recommendations of the President's Panel on Mental Retardation.

The Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963, in the form that finally passed Congress, authorized (1) funds for the construction of mental retardation research centers (MRRCs) and University Affiliated Facilities (UAFs), (2) grants to states to assist in the construction of specially designed community facilities for the retarded, and (3) grants to institutions of higher learning to train teachers of mentally retarded and other handicapped children.

The MRRCs were designed to conduct research and related activities dealing with human development to find the causes and means of prevention and amelioration of mental retardation. The University Affiliated Facilities were to be clinical facilities for services to the mentally retarded with services demonstration and personnel training components.

The section of the enacted legislation dealing with construction funds for the MR research centers authorized appropriations of \$6 million for FY 1964, \$8 million for FY 1965, and \$6 million each for FY 1966 and FY 1967. Within HEW, the Division of Health Research Facilities and Resources was given administrative authority for the construction phase of the Centers; and NICHD, which had been designated as the lead federal agency for mental retardation, was made responsible for Center program development.

By 1967, twelve Mental Retardation Centers had been funded, but none was yet in operation. Congress passed the Mental Retardation Amendments of 1967 but, as passed, they did not extend the authority for additional construction funds to build MR research centers. Subsequent mental retarda-

tion legislation and, more recently, developmental disabilities legislation have also failed to authorize further MRRC construction.

The MRRC construction legislation required a twenty-year commitment from each Center to use the buildings for mental retardation research. There was no legislative commitment of funds for program development.

Even before the 1963 legislation was passed, the question of the availability of adequate funding for the Centers was raised. The 1962 Report of the President's Panel said "support for [the Centers] should be drawn from State and private sources as well as from the Federal government." Testimony on the Mental Retardation Center construction bill urged adequate funding. In the June 1963 meeting of the NICHD Council, concern about the availability of operational funds for the Centers was raised.

In 1964, the Director of NICHD stated that NICHD should "support two-thirds to three-fourths of the research programs in centers." In 1967, NICHD's Office for Program Planning and Evaluation noted that "11 percent of NICHD funds are committed to research and training in mental retardation. Unless the center research program is implemented in the facilities now authorized and under construction, the research thrust in this area will be seriously jeopardized." In December 1967, the NICHD Director established a staff committee to study the concept of so-called implementation grants to provide some core support for the Centers and to establish Institute policy in this area. This committee recommended the establishment of a new review group, the Mental Retardation Research and Training Committee, and the de-

velopment of an MRRC grants program.

In its 1969 Fiscal Year budget submission, NICHD requested \$2 million to be earmarked specifically for MRRC support. The annual NICHD budget justification materials submitted to the Congress have commonly cited an Institute commitment to support a "major" share of the Centers' research and training needs. In the FY 1971 justification this was specified as 40 percent.

In 1969, the NICHD Council approved a policy statement that the adoption by NICHD of a specified area in which center development will be fostered . . . constitutes a moral commitment by NICHD to give continuing support, when merited, to the basic "center" operation so as to assure the stability of the undertaking for as long as it performs in a manner contributing to a mutually agreed upon mission of high priority to the NICHD.

The twelve MRRCs whose construction was funded under the original legislation are now fully operational. The support they receive from the NICHD Mental Retardation and Developmental Disabilities Branch (core support plus program project and individual research grants and contracts) comes to two-thirds (66.5 percent) of the total MRDD Branch budget of \$22 million as of 1976.

University Affiliated Facilities

As mentioned in the previous subsection, the legislation authorizing the funds to construct the MRRCs also authorized construction of so-called University Affiliated Facilities, which were originally designed to be clinical facilities to provide professional training and exemplary services in mental retardation. Unlike the MRRCs, however, the construction authority did not lapse at the end of FY 1967, but was amended to permit research to be included in the mandate of the UAFs. In 1970, the Develop-

the Social Security Act. MCH funds today support 21 UAF programs while DDO funds, in much smaller amounts, go to some 40. Using federal funding as the measure, there are now some 41 UAFs. The UAFs are collectively represented on the national scene by the American Association of University Affiliated Programs for the Developmentally Disabled.

Though the missions of the two networks, the MRRCs and the UAFs, are clearly distinct in many respects, closer collaboration between the programs, as well as among individual MRRCs and UAFs, would be likely to result in greater benefits for mentally retarded individuals and their families. The MRRCs focus on basic research in mental retardation and related aspects of human development, whereas the UAFs focus on developmental disabilities, which include several other conditions in addition to mental retardation, and concentrate on manpower development and exemplary service.

The Ad Hoc Consultants urge close collaboration between the MRRCs and UAFs, particularly those 10 MRRCs which are located in a university that also has a UAF. Such collaboration could significantly expedite the translation of research findings into services, and focus on clinical problems in need of solution through basic research.

Nonfederal Organizations

Mental retardation is an area that has attracted strong non-federal activity--at the level of state government, advocacy groups, private foundations, service organizations, professional organizations, private service suppliers, organized labor, and, most recently, the mentally retarded them-

mental Disabilities Services and Facilities Construction Amendments again extended the UAF construction program, through June 1973. However, no construction funds were budgeted or appropriated during the final years of this authorization.

In 1975, the Developmentally Disabled Assistance and Bill of Rights Act was enacted, continuing support for administrative and operating costs for the UAF program. The law also provided new authorization, for which only those UAFs which had already received federal money were eligible, to fund feasibility studies concerning ways that UAFs could establish and operate "satellite centers." The intent of this legislation, while unclear to many observers, appears to be to encourage the existing UAF network to move toward providing more direct services to more remote areas of the country.

For all intents and purposes, the MRRC and UAF programs are creatures of federal law, and the government has invested significantly in both of them. Its commitment to the UAFs has been the subject of considerable debate in recent years because of the multiple-agency funding which characterizes the relationship between HEW and that program.

The Developmental Disabilities Office (DDO) administers basic UAF authorization found in federal law, but has received relatively few funds to disburse. Within the Public Health Service, the Office for Maternal and Child Health (MCH) continues to administer the bulk of the federal UAF budget and does so on the basis of rather general language contained in Section 511 of

selves. Table 4 lists the main non-federal groups.

The foremost organization of public officials is the National Association of Coordinators of State Programs for the Mentally Retarded (NACSPMR). This group was formed five years ago as a nonprofit organization. It is funded by dues from the states, and the membership consists of one coordinator from each state. It was formed in response to the general concern about the wide disparities in mental retardation services at the state level.

The strongest of the advocacy groups, representing the service consumers, is the National Association for Retarded Citizens (NARC). Among private foundations, notable is the Joseph P. Kennedy, Jr. Foundation, with its Special Olympics and Families Play to Grow programs. Service clubs active in this field are the Jaycees and the Civitan Clubs. Outstanding professional groups include the American Association on Mental Deficiency and the Mental Retardation Division of the Council for Exceptional Children. Unions and employee bargaining agents such as the American Federation of State, County, and Municipal Employees are among the special interest groups who are active in the area. Private service suppliers include private residential schools (such as the National Association of Private Residential Facilities for the Mentally Retarded), foster homes, group homes for the retarded, and nursing homes (nonprofit and proprietary). Organizations of retarded persons themselves have been started, the leading example of which is "We are People First," statewide in Oregon with 17 chapters.

Numerous other groups can be classified as having special if not primary interest in mental retardation. Representative of these are the National Rehabilitation Foundation, the Epilepsy Foundation, and the United

TABLE 4

EXAMPLES OF NONFEDERAL ORGANIZATIONS ACTIVE IN THE
FIELD OF MENTAL RETARDATION

Accreditation Council for Facilities for the Mentally Retarded
 American Academy of Pediatrics
 American Association of Volunteer Services Coordinators
 American Association on Mental Deficiency (AAMD)
 American Medical Association
 American National Red Cross
 American Orthopsychiatric Association
 American Psychiatric Association
 American Psychological Association
 Association of University Affiliated Facilities
 Center for Law and Social Policy, Mental Health Law
 Civitans
 Council for Exceptional Children (CEC), Mental Retardation Division
 Epilepsy Foundation of America
 Health Insurance Association of America, Information and Research
 Division
 International Association for the Scientific Study of Mental Deficiency
 International League of Societies for the Mentally Handicapped
 Jaycees
 Joseph P. Kennedy, Jr. Foundation
 National Association for Mental Health
 National Association of Coordinators of State Programs for the Mentally
 Retarded, Inc.
 National Association of Private Residential Facilities for the Mentally
 Retarded
 National Association for Retarded Citizens (NARC)
 National Association of State Mental Health Program Directors
 National Center on Law and the Handicapped
 National Rehabilitation Association
 United Cerebral Palsy Association
 We Are People First (Oregon)

Cerebral Palsy Association.

Finally, there is also activity at the international level. The International Association for the Scientific Study of Mental Deficiency consists of more than thirty national organizations of scientists and professional

practitioners concerned with research in the field. The International League of Societies for the Mentally Handicapped represents parent organizations, professional groups, and individuals--in 1972 it had 39 national member societies and members in 57 countries.

III

WHAT WE KNOW AND WHAT WE STILL NEED TO DISCOVER ABOUT MENTAL RETARDATION

Mental retardation is commonly defined by the presence of several signs: a significant impairment in intellectual performance (often characterized as an IQ of 70 or below), a concurrent impairment in general adaptation, and onset of these manifestations before the age of 18 (the attainment of mental maturity).

What Causes Mental Retardation?

Mental retardation is not a phenomenon with a single cause. Many causes have been identified. But in only about one-quarter of cases is it possible, given the current state of our knowledge, to isolate a definite biological etiological factor and clinically identifiable somatic impairment. The major causes of these impairments have been proven to be chromosomal aberrations and metabolic disorders, many genetic in origin, and infections, either in utero or early in life. Most of these cases are profoundly retarded, with IQs usually below 50. Their incidence is uniform throughout the socioeconomic scale. They come to the attention of service professions early because their families identify something as wrong and bring them in spontaneously for diagnosis and treatment.

For three-quarters of the mentally retarded there are no identifiable physical characteristics. In contrast to the first group, they are usually only mildly retarded, with IQs in the 50-70 range. Also in

contrast to the first group, they are not usually identified by their families. They are usually diagnosed when they first go to school. They are identified because they perform in a way that is less intellectually adequate than a model member of society. Finally, the incidence of this second kind of mental retardation is correlated with socioeconomic status, being concentrated at the lower end of the scale.

Psychosocial disadvantage is routinely cited as the reason for the latter type of mental retardation. The etiology of "psychosocial disadvantage" is still completely unknown, although it is usually attributed to one or more of three causes.

The first cause cited is genetic--the view that cognitive capacities are unequally distributed because they are inherited and differ from family to family. The second involves nonheritable, environmental somatic factors--in utero, in the perinatal period, and in infancy. Mothers of such children have often been undernourished during their own development, become pregnant too young and too often, have a high incidence of low birthweight babies, and receive inadequate prenatal care. Their children in turn have poor nutrition and health care, and are often exposed to infections and other harmful agents and traumas. Effects are not identifiable by somatic examination, but it is reasonable to assume that the cumulative effects of such organic insults to the nervous system result in impairments to intellectual performance and general adaptation. The third kind involves child-rearing experiences--children who are unwanted, unplanned, or raised with fathers absent, and mothers who are emotionally or physically unavailable. "Sensory deprivation" is often identified as an important causative factor here.

Most authorities accept an interactionist theory, that genetic and environmental forces both impinge on intelligence. How much each contributes to the variance among individuals is still a matter of controversy. There is good research evidence to suggest, however, that the role of environmental factors is, in any case, sufficiently great that changes in a child's experiences can significantly change his measured IQ.

Enormous advances have been made during the past ten years in elucidating the etiology of chromosomal errors, inborn errors of metabolism, and infectious diseases. The work is not complete. Certain problems are still not definitively solved. The lines of inquiry are, however, relatively well-defined. New variants of previously identified conditions and new chromosomal aberrations are also still being regularly uncovered. But the incidence of these new conditions in the population is not large.

Our knowledge about the impact on intellectual development of environmental somatic factors and early childhood experiences, in contrast, though increasingly informed, lacks sufficient specificity for ready and feasible implementation. The association of mild retardation of psychosocial disadvantaged origin with the correlates of poverty—family pathology, single parent homes, malnutrition, poor hygiene, lack of mental stimulation, inadequate child rearing and maternal-child interaction, deficiencies in language and communication styles—is well-documented. It is likely, however, that these variables do not act singly as etiological agents but are additive in nature or interact with each other, and possibly with constitutional factors, in producing intellectual and behavioral deficits. These patterns of interaction and the social environmental conditions under which

they give rise to adverse developmental outcomes need to be precisely identified. Some of the intervention research currently in progress is promising in this regard. The research portfolio of the NICHD partially addresses these issues, but the efforts need considerable expansion and focus if solutions are to be found.

It should be explicitly noted here that, even at the lower end of the socioeconomic scale, the best prediction is that a child will not be retarded. The circumstances under which our less fortunate citizens live cannot, therefore, be singled out as central to the problem. These issues are far more complex than that.

What Are the Most Serious Knowledge Gaps That Remain
With Respect to Prevention?

The next major breakthrough in knowledge regarding mental retardation will probably come, in our judgment, in the neurosciences or perinatology; current efforts in biomedical research must be sustained and expanded. The behavioral and biobehavioral areas are important with respect to understanding retardation due to environmental influence. We must learn to understand the fundamental processes that govern the development of cognitive behavior.

Over the past decade there has been an explosion of research on human cognition, with major achievements in isolating independent stages of processing information and in the analysis of language and speech. There has also been rapid growth in the field of psychophysiology so that it is now possible to record subtle electrophysiological activity of the human nervous system during the performance of behaviorally important tasks. The combination of these two approaches would seem especially promising. Such

fundamental behavioral and biobehavioral research on the developing nervous system should certainly prove fruitful in discovering how somatic injury and early experience produce the syndrome of mental retardation.

Fundamental research and development of methodologies for understanding the processes that constitute cognitive development and dysfunction are urgently needed. Studies in early infancy may be particularly rewarding, since growth is very rapid at this stage of development. In recent years there has been great progress in understanding normal development during early infancy, but the surface has barely been scratched, and there has been far too little study of the high-risk infant in this connection.

Another major gap in our knowledge that must be remedied is in the area of indicators of social (as opposed to strictly cognitive) development. This has become an increasingly important issue in defining and diagnosing mental retardation as we trust IQ measures less and less. The need to develop adequate indicators of social development has been recognized and commented on for ten years. We are aware that efforts continue to be made; but they have not yet been successful. Existing scales are still too unrefined and undifferentiated to be effective in diagnosis or in elucidating the relationship between cognitive malfunction and difficulties experienced in social processes. We keep measuring what is easy to measure rather than what we need to measure to fully understand social inadequacy, the central problem of mental retardation.

One reason for this failure is that most of the existing behavior scales have been standardized on the low-level and institutional populations, rather than on the bulk of the mentally retarded who are in the

community. We need investigators with a social interaction approach who have a sustained interest in mental retardation.

A final, extremely important consideration in developing scales to measure social development is to understand that, when we measure social competence, we have to talk about social norms. We must recognize that the definition of competence is itself a social phenomenon, which suggests the importance of interdisciplinary approaches to this measurement task.

So far the discussion has been concerned with finding out if and why certain causes have certain effects on the developing child. There is another level, equally important in our view, at which increased knowledge will improve our ability to prevent mental retardation. This is at the level of studying the behavior that produces situations which place the child at high risk for mental retardation. The examples we shall discuss here are (1) prematurity and low birthweight, and (2) nutrition.

The frequency of prematurity and low birthweight in babies is twice as high in the population at high risk for mental retardation as in the general population. If the biological causes of prematurity and "small for date" babies were identified and prevented, a quantum leap would be made in preventing the birth of such babies with their increased risk of mental retardation.

For this reason, study of the mechanism regulating the onset of labor is a high-priority research item. If we could prevent women from going into labor until their babies are of adequate size, we could make major progress. More research is also needed, from a biological point of view, on the optimal age and conditions for reproduction. This should lead to such research questions as: Can we increase the chances that people have babies

at the optimal age? Can we improve child-bearing chances at other ages? Viral infections, drug ingestion, and emotional stress are also known to influence pregnancy outcomes, but the precise mechanism of their influence is not known. The role of the father as an early caretaker is known to be important and also largely unresearched.

The effects of suboptimal reproduction age, too frequent pregnancies, and poor child-rearing environments come together in the teenage pregnancy. If we are interested in preventing mental retardation by elucidating its etiology, we must also be interested in what produces teenage pregnancies. The question of why adolescent girls become pregnant is fully as important as the question of what constitutes good care in pregnancy once it occurs. Increased availability of contraceptive information and abortion is not significantly lessening this problem. It is also true that teenage mothers, in spite of psychological and social pressures, are increasingly unwilling to give up their babies for adoption. Why do teenage women become pregnant, many not once but several times before they reach their twentieth year? There is evidence that the action is, at some level, deliberate—pregnancy is seen as a way to gain status, to escape from the previous social situation. Further behavioral science research is needed to elucidate this important question.

Studies of nutrition are also vital to the ultimate prevention of mental retardation. We do not need more research to know that we should feed people when they are hungry. We do not need more research to show that, up to a certain income level, the more money people have, the more they spend on food. We do need more research to test the current nutritional theories of pathology. We need further research to find out whether protein intake

has clear effects on intellectual development. We need further research before we can specify exactly what an optimal diet for a pregnant mother would be. We also need research on the effect of early nutritional deprivation or excess on the development of adult disease and disorders.

But when we have definitively established all this, we will still not be in a position to use this knowledge to foster prevention of mental retardation. Nutrition not only has physical consequences; it also has psychological, social, and educational foundations and consequences.

People have deeply ingrained nutritional habits, often based on tradition, and they are reluctant to change them. There has been very little good analysis of the nutritional value of ethnic subgroup diets. Until we have that information, we shall not be able to specify needed supplements. The last and possibly the most intractable problem is: How can people be persuaded to change their diets? For example, there are mothers who eat laundry starch when they are pregnant. To stop them we need more than public information campaigns; we need to know why they eat the way they do, and why they are unwilling to change their habits.

The area of child nutrition needs further research. Currently, the value of the nourishment itself cannot be separated from the manner in which it is offered as a reflection of maternal responsiveness, i.e., the child's immediate social environment. The relationship between nutrition and educational achievement in school is another complex issue with behavioral components. This is an important educational issue highlighted by the Head Start experience, because for some children the Head Start meal is the only meal. The question is not whether we should feed these children. We should.

It is a question of whether feeding alone will help. Does the child show apathy at school because he is malnourished? Is he simply hungry? Will good food raise his attention span, or is the problem a more general environmental one?

Other Priority Research Areas

The ultimate goal of mental retardation research, simply stated, is to reduce the incidence of mental retardation. A related important goal (in cases where mental retardation cannot be prevented) is to discover means of minimizing the deleterious effect on the lives of the victims of mental retardation and their families.

In this connection, even basic descriptive research on the retarded is badly needed. Apart from the definitional questions raised earlier in this report, there are important demographic questions on the mentally retarded population that we cannot now answer. A second category where there are major gaps in our knowledge concerns the characteristics of the retarded. A third area in which extremely little has been done concerns the effects of different social and caretaking settings on the retarded, and the effects of the mentally retarded on the people and organizations around them.

Demographic Information.--We have, in fact, extremely little demographic information concerning the mentally retarded population. For instance, there have been few studies investigating how the mentally retarded population changes over time. We know that the prevalence of mental retardation is related to age, with the highest incidence during the school years. Except for the shape of the epidemiologic curve, however, the subject is un-researched. We know that the rate of sexual development is related to the profile of cognitive abilities, a fact which raises specific issues in terms

of mental retardation. In recent years certain sex-chromosome abnormalities have been found to be associated with specific learning disorders (defect in spatial learning in Turner's Syndrome; speech problems in XXY Syndrome). But we do not know the characteristics of those who enter the mentally retarded population and then disappear from that category as they leave school, or of those who remain within the category, or of those who become more deeply retarded as they mature.

There are also no lifespan studies of the mentally retarded. This must be remedied--the urgency of such knowledge increases as deinstitutionalization proceeds. We do not, to cite a specific example, know something as obviously relevant as the life expectancy of the retarded.

Another demographic question we cannot now answer is the effect on the mentally retarded population of the expanding use of genetic counseling, and the increased knowledge and availability of both birth control and abortion. Are these developments in fact reducing the mentally retarded population? We do not know the effects of salvaging high-risk infants due to the success of intensive care units. Are the graduates of intensive care units increasing the mentally retarded population? Studies in progress will provide data on these issues. These are longitudinal studies that do not yield meaningful results until sufficient data are collected over a time period.

Characteristics.--There are also important unresolved issues concerning the characteristics of the retarded. There is a body of conventional wisdom, but much of it is unsubstantiated by systematic research evidence. For instance, little is known about the mores and morals of the retarded. What research has been done, in this as in so many areas, has been based on

institutional populations. The mentally retarded have traditionally been viewed as highly dependent individuals and as having extremely strict moral standards. We have no systematic information, however, regarding their sexual activity, including their willingness and ability to use sex education or contraception.

There is also a dearth of information regarding the link between mental retardation and delinquency. The state prison system certainly has its share of prisoners who are retarded. Many children seen in juvenile court are either mentally retarded, or emotionally disturbed, or both.

Another important issue is the susceptibility of the mentally retarded child to accidents and to child abuse. The highest cause of death in children after the first year is accidents. Every year between one-and-one-half and two million children fall off something more than three feet high. The stereotype of the parent of a mentally retarded child as overprotective might lead one to expect the mentally retarded child to be less a victim of accidents than normal children. There has never been a study of accidents in the retarded population, so we simply don't know. Abuse of the mentally retarded child is another subject on which we have no hard evidence. The best hunch is that a child with any form of anomaly may be at greater risk. There is some evidence that normal children who are abused are most likely to be physically abused. Abnormal children seem to suffer predominantly from nutritional and psychological abuse.

Perhaps the most interesting new development in this general area is the effort to construct models in which both accidents and child abuse are

reflections of certain stress phenomena and have a similar etiology. Abuser parents seem to lack the normal social networks that provide emotional support--a lack known to be damaging for any parent. This issue with respect to the parents of the mentally retarded has not been researched.

The Mentally Retarded and Their Environment.--Most studies of the mentally retarded have examined them in isolation--that is, abstracted from their effect on the environment around them and from the effect of their environment upon them. By environment we mean the family or group of people with whom they live; the school to which they go and the teachers and other children in that school; the community in which they pursue their daily lives; and the bureaucracies responsible for giving them treatment and other services.

All forms of family care--natural parents, foster families, substitute and supplementary parental care--must be studied. Research in this area to date is extremely sparse. Of particular importance are the new forms of family that are developing and the relationships between the children and adults who form the family group. In particular, the study of the single-parent family and what it means psychologically has not kept pace with the increase in its prevalence in the U.S. Such families make up an increasing proportion of America's poor and the incidence among them of child abuse and neglect is higher than that among two-parent families. We do not want to be viewed as critical of parents who choose to bring up their children alone; however, involuntary loneliness plus family responsibilities can become an intolerable burden.

The impact of the birth of a retarded child on the family unit also needs study. Many of these babies have been isolated from their families

for an extended period before the initial relationships between parent and child can be formed. The birth of such a child must also cause stress on the relationship of the adults to each other, with resulting effects on that child and on other children.

Another issue rapidly assuming tremendous importance is study of the mentally retarded child in relation to the school system. With the advent of "normalization" and "mainstreaming" on a large scale, millions of dollars are now being spent on mainstreaming at the state level, and we know little from a research point of view about its probable effects. Since mainstreaming is not being applied uniformly, the effects probably differ in various school systems. It is important that evaluative studies of these various programs be undertaken early, so that we have reliable data for future program development.

While models have been developed for the behavior of parents toward a retarded child, there are no models for the school system's behavior towards him. There is a general literature on contextual effects of the integration of various ethnic and socioeconomic groups into the school system, indicating that the effects on the child's development are very complex. This same methodology should be applied to the mentally retarded.

Another important issue is the effect of the presence of the retarded child on the teachers and the other children. Research has shown that the retarded child placed with nonretarded children is invariably disliked. It would be surprising if this did not have an effect on his emotional life. There is also evidence that the presence of the retarded in the classroom arouses anxiety, even anger, on the part of the professionals who deal with them. How do you prepare people for the presence of a retarded child in the

schoolroom? Good research must be done on these issues. There is a real danger that the retarded may be harmed by the backlash from a policy designed for their benefit.

The effect of television on the retarded is another issue about which little is known. The presence of television reduces the interaction among adults and children in all settings. It would be reasonable to assume that parents (and others) with a mentally retarded child use the television set as a distraction for the child. We have no idea what this reduced adult/child involvement is costing in its effect on normal children. If adult/child interaction is more important in the development of a retarded child, that cost will be correspondingly higher.

Another facet of the television issue relates to influencing community attitudes toward the mentally retarded. There is evidence, for instance, that communities do not want the retarded in their neighborhoods. Deinstitutionalization is making community attitudes a socially important issue. How can that attitude be changed? There has been no adequate study of the potential impact of the media. The technology for such studies exists; now the right questions must be asked.

Psychological and sociological studies of the bureaucracies that deal with the mentally retarded are needed. People dealing with the mentally retarded themselves have interests and problems that shape their actions. The social agency is an organizational mechanism whose functions have implications for the mentally retarded. The Community Mental Health Centers, for instance, exclude the mentally retarded. The source of such resistance is another important subject for study.

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Specific recommendations for high-priority research appear at the end of the next section.

IV

PAST ACCOMPLISHMENTS AND RECOMMENDATIONS FOR THE FUTURE

In the final section of our report we address the problems and opportunities of the two Institutes that are the special focus of our charge. The first subsection discusses the current activity of NICHD with regard to mental retardation, and makes certain recommendations. The second subsection discusses and makes recommendations on mental retardation activity in NIMH. The final subsection discusses ways in which NIMH and NICHD might complement one another's strengths, and provides a priority list of mental retardation activities. Included also are problems that we feel need the cooperation of specific other government agencies, in addition to NICHD and NIMH, for lasting solutions.

We did not provide a list of specific problems that we felt were the responsibility of NIMH alone. Since NIMH has been virtually uninvolved in MR related issues for more than a decade, only the future will clarify what may be NIMH's special focus as it expands its MR activity.

NICHD: Past, Present, and Future

When the NICHD was established in 1963, as Section II of our report has described, one of the major reasons for its establishment was to create a national focus for the major social problem of mental retardation. The Institute, as finally established, had a broader focus--all human growth and development. Mental retardation is, at least in large part, a failure of the normal processes of human growth and development. Expansion of our knowledge

about mental retardation cannot come about without further understanding of those normal processes. In this sense, we endorse the philosophy of interpreting mental retardation research broadly. We also want to emphasize that, although NICHD is appropriately concerned with all aspects of research on human development, it has an extra responsibility to attack important research areas that do not overlap with what is already being done but do involve the mentally retarded directly.

Mental Retardation and Developmental Disabilities Branch (MRDD).--

Twenty years ago, mental retardation was not a respected area of research. The quality of the work being done was generally poor, limited in the extent of the phenomena being investigated, and largely sterile in regard to theoretical formulations to guide either researchers or practitioners. The textbooks in the field were, by today's standards, narrow and surprisingly naive.

Today, there are several first-rate textbooks as well as many excellent research monographs, including the Mental Retardation Research Centers Conference Series sponsored by NICHD: excellent articles on mental retardation now appear regularly in all the major journals; and the general quality of America's major journal reporting mental retardation research, the American Journal of Mental Deficiency, has improved so much that it is hard to recognize as the spotty journal of years ago.

The major research advances have been in the areas of genetics, inborn errors of metabolism, and the role of infectious diseases. Progress in these areas has led us to recommend that the major research priorities in

the area of mental retardation now be expanded to include neurophysiology and biobehavioral and behavioral sciences.

Mental Retardation Research Centers.--As described earlier, the Federal Government made a major financial commitment during the 1960s in the form of construction grants to twelve universities to build Mental Retardation Research Centers. These universities, in turn, were committed for twenty years to use the buildings for mental retardation research. A major part of the funds of the MRDD Branch of the NICHD now goes, in one form or another, to support the research pursued in the MRRCs. Last year, the proportion was between 60 and 65 percent.

The Centers, in our judgment, have had a unique impact on the field. First, the impact of a twenty-year commitment by academic institutions around the country gave mental retardation a visibility and an emphasis, as a field, that it otherwise would not have received. University presidents and administrators were forced to build it into their planning on a continuing basis. Second, the stability provided by the twenty-year commitment attracted outstanding scholars into the field who would not have made such a career investment without long-term assurance of support. Third, the MRRCs were committed from the start to an interdisciplinary focus as a condition of their construction. This, in turn, fostered the communication among disciplines that, in spite of the obvious problems, we have earlier specified as essential for major progress in the field. Fourth, the existence on university campuses of such substantial institutions as the MRRCs caused scholars not funded or directly connected with the Centers to become, as a consequence of the work of their colleagues, interested in the research issues confronting

the field.

We are wholeheartedly in favor of retaining the core grant concept. Our primary reason is that the twenty-year commitment on the part of the universities should be met with analogous support from government. As previously noted, the initial MRRC legislation did not provide for such support. The NICHD, however, has consistently promised such support, and it would be poor public policy to abandon this concept. Our second reason is that some long-term stability of funding is essential if high-quality research on large problems is to continue. There are short-run fads in research as in other areas. Long-term funding enables valuable, if momentarily unfashionable research, to survive such vicissitudes.

Whether the proportion of funds now going to core support of the Centers is reasonable, however, is not entirely clear. We have reviewed all the evidence at our disposal regarding the mental retardation research going on inside and outside the Centers. The current division has evolved pragmatically. We do not feel that the evidence is available, either to us or to the Director of NICHD, to make an informed judgment.

To ensure that major imbalances do not occur, the proportions should be regularly reviewed, from the viewpoint of the goals of MR research, at the staff level where the allocation of funds is decided. No single evaluation technique can be adequate to the task. A wide range of criteria should be used. We have formulated nine:

1. The degree to which peer review rating scores diverge between Center research and outside research.

2. The degree to which the Centers are successful in promoting real interdisciplinary research compared with program projects outside.
3. The degree to which citation indexes include Center-sponsored research.
4. The degree to which the existence of the Centers continues to promote major long-term sustained research.
5. The degree to which Centers continue to recruit quality researchers into the mental retardation field.
6. The continuing impact on universities and their administration of the Centers.
7. The degree to which outside consultant evaluation continues to judge Center research as distinguished.
8. The degree to which the work of the Centers has an impact on the retarded in their area.
9. The degree to which the Centers maintain ties with a service component.

We were able to make some assessment in terms of criteria (1), (2), and (3), and have made a tentative judgment that there is no gross imbalance between research inside and research outside the Centers.

We end this discussion of the MRRCs with two comments. First, the Centers were established as a direct charge from Congress. The charge was implemented and implemented well--in itself an important achievement. The Centers should certainly be maintained. But decisions concerning funding and planning priorities will continue to arise. NICHD has a responsibility to formulate an adequate set of criteria, which define the accountability of the Centers, as a basis for making those budgetary decisions.

Program Project Grants.--We reaffirm the desirability of the program project approach with free competition within and outside the MRRCs. Our review of the evidence shows that outstanding program project proposals are attracted and funded which enable important interdisciplinary work to be undertaken. They also provide some of the funding stability essential, as we have mentioned earlier, for long-term quality research. The longer time frame makes possible the investigation of problems too complex for short-term proposals, with the necessary larger commitment of people, money, and facilities. In particular, the limited data we have suggest that the program projects are at least as good as, and possibly better than, the individual research grant mechanism for supporting research undertaken within the shell of the core grants.

We endorse the program project concept in full recognition of the fact that it involves large amounts of money, particularly for the MRRCs when added to the core grants, and puts the individual beginning investigator at a relative disadvantage.

Behavioral Sciences.--When we undertook the assignment of evaluating mental retardation activity in NICHD and NIMH, we were aware of the subjective expressions of concern that have been increasingly expressed regarding the weight given to the behavioral sciences in NIH in general and NICHD in particular. Given our view that the behavioral sciences are important with respect to prevention as well as amelioration in the mental retardation area, we addressed as a serious issue the place of the behavioral sciences in the budget allocations within NICHD. Table 5 shows the proportions going to the behavioral sciences of the grants and contracts awarded by the two NICHD centers over the period 1964-1976.

TABLE 5

PROPORTION OF NICHD GRANT AND CONTRACT FUNDS TO
BEHAVIORAL SCIENCES, BY CENTER, 1964-1976
(\$ millions)

	NICHD*		Center for Population Research		Center for Research for Mothers and Children	
	Total	% Behavioral	Total	% Behavioral	Total	% Behavioral
1964	\$ 24.05	13.8	\$ 3.32	5.5	\$20.73	15.1
1965	32.44	18.1	5.30	15.2	27.14	18.7
1966	41.59	19.7	6.32	9.4	35.27	21.5
1967	46.82	23.0	7.98	10.6	38.85	25.5
1968	47.55	25.7	8.65	13.7	38.90	28.4
1969	50.44	24.8	11.90	16.3	38.54	27.4
1970	54.98	24.0	17.39	17.6	37.59	27.0
1971	69.83	27.5	26.40	26.0	43.43	28.4
1972	85.44	23.9	35.76	19.2	49.68	27.2
1973	81.04	21.0	34.66	16.6	46.38	24.3
1974	106.37	23.1	45.54	22.5	60.83	23.6
1975	106.77	22.2	44.59	21.8	62.17	22.5
1976	113.88	22.7	46.94	20.0	66.94	24.6

* Excludes the Adult Development and Aging program, now National Institute on Aging (NIA). Also excludes scientific evaluation grants.

For NICHD as a whole, the proportion of grant and contract money going to the behavioral sciences (including the biobehavioral fields) increased from 13.8 percent in 1964 to a high of 27.5 in 1971.* Since then it has declined to 22.7 percent in 1976. These overall averages conceal differences between the two centers within NICHD, the Center for Population Research (CPR) and the Center for Research for Mothers and Children (CRMC). The Center for Population Research allocated only 5.5 percent of grant funds in 1964 to the behavioral sciences; this has increased over the period to 20.0 percent in 1976. The Center for Research for Mothers and Children, which was created to combine three separate branches about a year ago, started with 15.1 percent of its grant and contract funds going to behavioral science in 1964.# This proportion grew to 28.4 percent in 1968 and 1971, and it has since gradually diminished to 24.6 percent in 1976.

When the CRMC funds are disaggregated by branch the reason for this decline emerges, as can be seen in Table 6. Within both the Growth and Development Branch (GD)+ and the Mental Retardation and Developmental Disabilities Branch (MRDD) the proportions going to behavioral science have declined. The proportion in GD declined from 44.9 percent in 1970 to 32.3 percent in 1976. In MRDD the proportion declined from 44.2 in 1968 to 33.1 in 1975. (The 1976 MRDD increase principally reflects new means of distributing the Institute budget.) GD and MRDD have provided the major support of fundamental behavioral research on developmental problems. In the Pregnancy and Infancy Branch, in contrast, the proportion has remained relatively stable but has never been more than 1.2 percent of total grant and contract.

* Excluding the Adult Development and Aging Branch, now in NIA.

Grants and contracts have been retroactively reassigned according to present criteria, for comparability.

+ See footnote, page _____.

TABLE 6

PROPORTION OF CRMC GRANT AND CONTRACT FUNDS TO
BEHAVIORAL SCIENCES, BY BRANCH, 1964-1976 *
(\$ millions)

	Pregnancy and Infancy		Growth and Development		Mental Retardation & Devt'l Disab.	
	Total	% Behavioral	Total	% Behavioral	Total	% Behavioral
1964	\$ 7.94	<u>a/</u>	\$ 9.76	18.8	\$ 3.02	42.7
1965	9.78	0.1	13.68	25.7	3.69	41.6
1966	12.58	0.1	17.71	32.8	4.98	35.7
1967	13.74	0.6	19.01	38.7	6.10	40.5
1968	13.35	1.0	18.69	42.2	6.86	44.2
1969	13.56	1.1	16.46	43.8	8.53	37.5
1970	11.80	1.0	15.74	44.9	10.04	29.5
1971	12.43	0.9	16.97	43.7	14.03	34.4
1972	14.06	1.2	16.90	43.2	18.72	32.3
1973	14.09	1.2	14.70	36.8	17.60	32.3
1974	20.34	0.3	20.29	36.2	20.20	34.2
1975	22.25	1.1	19.51	35.7	20.42	33.1
1976	23.65	0.8	21.28	32.3	22.01	42.7

a/ Percentage is smaller than 0.05.

* Excludes scientific evaluation grants.

funds.

Another difference among the three branches is conspicuous. The Growth and Development Branch funds have grown relatively little in the past decade while there have been large increases in both the Pregnancy and Infancy and the Mental Retardation and Developmental Disabilities Branches so that the three branches are now roughly equal in the absolute dollars supporting research. However, the infusion of new funds for pregnancy and infancy research has not been accompanied by any increase in the proportion of behavioral research, which is still almost nonexistent.

Concern expressed about the relative deprivation of behavioral science at NICHD has, thus, an objective basis in fact. The decline in support by the Growth and Development Branch is particularly important since this branch supports the bulk of investigator-initiated research on normal development.

We have already stressed that research into the normal processes of human development is crucial to the elucidation of mental retardation. Such research need not necessarily be funded by the MRDD Branch; but it is important to mental retardation that it be done and done appropriately. Since behavioral science research makes a major contribution to knowledge concerning both normal and abnormal developmental processes, there should be an appropriate balance between the biomedical and behavioral sciences in every branch of the Institute.

Let us cite a single instance to make our point. The set of incidents involved in low birthweight and subsequent isolation in the intensive care unit has extremely important behavioral consequences for development. That the Pregnancy and Infancy Branch allocates less than 1.5 percent of its grant and contract funds to behavioral research is not reassuring.

We have four general observations to make about this situation. First, it is a programmatic rather than an economic analysis that gives rise to the concerns we have just expressed. If one is going to do something about prevention, rather than simply study the process or the outcome, one has to look not only at the biological context but also at the behavioral and social contexts. Because of shifts in funding from branch to branch, decisions are being made for NICHD as a whole that are reducing the proportion of behavioral science research. This causes us concern.

Second, we have no basis for saying that there is a "right" proportion, or a deserved proportion, or a politically expedient one. Attention must be paid on a continuing basis, using the same kinds of evaluative criteria listed in the previous subsection, to make sure that the funding proportions going to different disciplines do not become distorted.

Third, if we accept the premise that in order to understand certain phenomena relevant to the mission of NICHD we need the expertise of the social scientist, then we must encourage the community of scholars to do the research relevant to that mission. If quality research is to be fostered, the funding possibilities must be made attractive enough for competent researchers to apply.

Fourth, in order to competently carry through behavioral science programs, the Institute must ensure appropriate staffing. Attention should also be given at the Director's level to facilitating communication among the individual branches.

Share of Funds Going to the MRDD Branch.--Here, as in our previous discussions of funding priorities, we do not have a firm view as to the appropriate distribution of funds among the various branches. The Director will have to develop a wide set of evaluation criteria, as in the other funding

decisions already discussed, in order to be able to judge whether a change in the distribution of branch funds is appropriate.

We noted earlier that the MRDD Branch has been growing more slowly in the 1970s than the other two branches. This may be appropriate. Catch-up periods for different branches at different times are certainly necessary. We do take this opportunity to say that there is great need for further MR-related research. If research applications of high quality come in on any or all of the unanswered questions raised in our report, the amount now spent on MR could be doubled without wasting a penny.

The high proportion of the MRDD Branch budget going to core support for the MRRCs does, of course, reduce the scope of the MRDD Branch's ability to fund research proposals. The core support funds do provide support for MR research, however. Continuing assessment of the quality of Center research, as discussed earlier, is the appropriate way to decide whether the core funds represent too high a proportion of total branch funds.

National Institute of Mental Health

For various historical reasons--including the fact that mental retardation was emerging as a field no longer to be subsumed under mental illness--the National Institute of Mental Health has had practically no activity in the mental retardation area for ten years. The only exception to this has been a small, although high quality, research portfolio. The consultants heartily welcome the invitation of the NIMH Director to consider the feasibility of renewed participation in the field.

We have no hesitation in stating that NIMH should reenter the field,

not only with respect to research but also with respect to training and service. NIMH's stance over the last decade has, in our view, constituted discriminatory behavior against the mentally retarded.

Mental retardation is by definition a symptom of aberrant development. Research into its etiologies, prevention and amelioration is, therefore, relevant to the child health and human development mandate of NICHD. Disorders of cognitive development and socially deviant behavior, however, also have important implications for the mental health mission of NIMH. The prevalence of emotional disorders in the mentally retarded is very high, with serious consequences for formation of the self-concept, personality development and social adaptation. The disruptive impact on family life and resultant demands on the community for mental health and related services support the need for a vital role for NIMH in the mental retardation field. The broad authority of NIMH to support research, service and training places this agency in a unique position to address the mental health needs of the retarded and their families.

The first, most urgent, need is to reintroduce mental retardation into the purview of the Community Mental Health Centers (CMHCs). There are now 603 CMHCs in operation--in all fifty states, the territories, and the District of Columbia. Mental health treatment is thus accessible to 87 million citizens--except, to any meaningful extent, those who are mentally retarded.

The systematic exclusion of the mentally retarded from the CMHCs is not only discriminatory; it also makes impossible the fulfillment of the CMHC charge to provide sound diagnostic services. Most people seeking services do not know the nature of their need. NIMH, by ignoring mental retardation in its training programs for the past ten years, is well on its way to producing

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a generation of mental health professionals who are totally unsophisticated in mental retardation. Thus, it is no longer assured that if a mentally retarded person seeks help in a Community Mental Health Center his disability will be recognized and, if recognized, can be treated.

We think it important for the CMHCs to acknowledge explicitly that the diagnosis and treatment of mental retardation is one of their responsibilities. To fulfill their responsibilities with quality services, the CMHCs will need to initiate a broadly based staff development and in-service training program on the mental health aspects of mental retardation, and expand the interdisciplinary composition of center staffs. The NIMH could facilitate the role of the CMHCs in mental retardation through university training for mental health professionals. This latter goal may be accomplished without supplementary training grant support; however, the staff development program recommended would undoubtedly require additional funding.

The second need is to expand the NIMH portfolio of MR-related research. This, however, is not an easy task.

NIMH is in a period of budget decline, not only in real terms, but even in money terms. In 1967, the research budget for all components of NIMH was just under \$104 million. Today, excluding research activities in alcohol and drug abuse, the NIMH research budget is \$96 million. The decade thus resulted in a 7.6 percent decline in research funds in money terms. When inflation is taken into account, the decline in real terms over the period has been 31 percent. In contrast, funds for the research programs of NIH increased over the past decade by 34 percent in real terms. Even the worst cut to the Institutes within NIH, that to the National Institute of Neurological

and Communicative Diseases and Stroke (NINCDS), was 22 percent as compared to 31 percent for NIMH. We should note here our consternation with the general trend throughout the Public Health Service--that is, that the Institutes cut the most are the brain-related and behavior-related ones. When one considers that the future of man hinges on the optimal development of the central nervous system, the trend is ominous.

Before NIMH can expand its MR research, additional funds must be found. There is no program area currently supported by the NIMH budget that can be responsibly cut. Nor is there any money in NICHD which could profitably be transferred to NIMH.

In order to gear up for expanded activity in the MR field, the Director of NIMH should take two staffing actions. First, he should designate a member of his senior staff to be responsible for implementing our recommendations. Second, he should appoint to the NIMH staff at the program level someone whose substantive interest and expertise lie in mental retardation research. If staffing constraints are such that a permanent appointment is not possible, this person could perhaps be a university-based researcher appointed to NIMH for two years while on leave from an academic position.

Another step we recommend is that the Director convene an intramural group to develop an internal plan for NIMH with respect to possible avenues for new action on mental retardation. When such a plan has been developed, he should convene a public (consumer) group to evaluate it for feasibility and outside acceptability.

As more money becomes available, NIMH should expand its MR-related research along the lines discussed in the subsection below on possibilities

for joint cooperation. We have chosen to present a long list of suggestions rather than to offer a small number of firm recommendations because we feel that, although NIMH should develop its own approach as it reenters the field, the details of that approach are best left to evolve with time.

Relationship of Research to Training and Service

As will be clear from the amount of attention we have given to research, we feel that the most urgent need is for continued research into the nature and causes of mental retardation. We are in a period of general retrenchment in the human services area. If a social problem becomes sufficiently visible and dramatic, money is appropriated. The effort is very likely to have a predominantly service orientation, because people seek action. Action cannot be effective, however, until the basic knowledge exists upon which to make informed choices. Research cannot promise that ten years from now all problems will be solved; it can promise to deliver the informed alternatives policymakers need in order to act responsibly.

There are two important considerations in addition to research, and we deal with them to some extent in this subsection. The first includes manpower and training needs for research and service. The second includes translation of research findings into forms which can be used by practitioners and by the public.

Manpower and Training Needs.--We do not have the systematic data necessary to give any quantitative assessment of manpower and training needs. We recommend that the Director of NICHD use one percent of evaluation funds to investigate what is happening to the graduates of the MR training programs

and to make an assessment of future needs.

We do have certain evidence, admittedly anecdotal, to suggest that the MR training grants should certainly not be cut further and should perhaps be expanded. First, the rate of placement and quality of jobs available have not declined for individuals coming out of the interdisciplinary programs. This, particularly in view of the generally declining academic market, is an indication of the need for these graduates. Second, service-related operational researchers are needed in every state, and the pipeline is not now filled. Moreover, there is a need at the state level for middle-level and leadership posts in the MR programs, while currently the available pool of prospective personnel is extremely small. The state systems employ very few people who can deal with MR issues with any real knowledge. Here again NICHD should use one percent evaluation funds to assess the need for MR-trained people in the state service systems.

The question is sometimes raised whether, given that the major markets are at the state level, training is really a federal responsibility. We conclude that it is. First, research is generally agreed to be a federal responsibility, and responsibility for generating appropriate manpower to carry out that research should be at the same level of government. Second, researchers are one of the most mobile groups. For this reason, states are unlikely to be willing to assume financial responsibility for fulfilling the need.

The fact that we have stressed the interdisciplinary nature of the training also deserves discussion. Even though interdisciplinary training has not been as successful as anticipated, this is the kind of training most

relevant to MR, given the nature of the problem. Let us give one example: ultrastructure chemistry and intracellular neurophysiology are totally inter-related subjects. In traditional academic settings one must go to the Department of Pathology to learn ultrastructure and electron microscopy, to the Pharmacology Department to learn neuropharmacology, and to the Department of Neurophysiology to learn intracellular recordings. One of the major problems with federal research training grants over the past thirty years is that they established a strictly disciplinary system--an action at least partly responsible for the oversupply in certain fields.

We may not need augmentation of the total research pool. We certainly need to increase the cadre that is genuinely interdisciplinary. And we do not think this can be effectively done by retraining people from already crowded fields. The best talent, in general, cannot be attracted into other areas of research by new money--at least in the short run.

Translation and Dissemination of Research Findings.--We do not agree with the view often expressed that research will automatically find its way into the health care delivery systems or to the public. A certain proportion of funds must be devoted to finding effective ways to perform the transition.

What is missing is an analog to product development by engineers in industry. A few effective models of information programs have been designed and put into use by NICHD, but these are exceptions to a general paucity.

In our view, the incentives to undertake such product development do not exist. Investigators have little incentive to develop their research (or that of others) into readily usable form. Academic departments do not

reward such work, and the review system of the study sections does not rate such research applications very highly. The incentives are also absent for the practitioners, who are interested in continuing to do what they already know how to do. It is in the interest of the funding agencies to develop an effective reward structure. Without it, the translation problem is unlikely to be solved.

Future Cooperation Between NICHD and NIMH

We have already stated our view that there should be no transfer of funds between NICHD and NIMH. The Mental Retardation and Developmental Disabilities Branch at NICHD is making effective use of its budget. In any case, at existing staff levels, NIMH has no personnel available to supervise such funds if they were to be transferred.

To fulfill its responsibilities to the mentally retarded, therefore, NIMH will need new funds. Within the framework of a budget that is actually declining, we see no conceivable way that any existing NIMH program can be cut to free money for another purpose.

Assuming the acquisition of an additional budget, we feel that cooperation should be pursued in such a way that the relative strengths of the two Institutes can be used to complement one another. The Institutes should pursue together the ways in which they can be more effective working jointly. There are several obvious differences that should be creatively exploited.

1. NICHD is totally a research institute; NIMH combines research, training, and service.
2. NICHD is currently stronger in the biomedical sciences; NIMH in

the behavioral sciences. This carries with it the implication that the regular grant recipients of each belong to different academic clusters.

3. NICHD sees its mandate as predominantly infancy and early childhood; NIMH includes children, youth, and adults within its focus, including behavioral interactions between these groups.

4. NIMH has a network of 603 Community Mental Health Centers that currently neglect the mentally retarded. NICHD's expertise in MR is needed if NIMH is to meet its moral commitment to provide effective services to all its clients.

5. NICHD has a tie with ten of the University Affiliated Facilities. The experience of NIMH in training service workers and incorporating research into a treatment setting could be useful to NICHD in this connection.

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Our report ends with an extended list of items which, in our judgment, should receive high research priority from NICHD, NIMH, or both. Some of them also specify input from a third agency. If further collaboration should fail to materialize, some of them could be pursued by NIMH alone.

Development of methodologies to understand the nature of the processes that constitute cognitive development and dysfunction. This work should include attention to early measures of cognitive and language development, discriminative measures of mother (caretaker)-child interaction, and discriminative measures of the component stages of information processing and how they relate to physiological change.

Longitudinal studies of high-risk infants. In recent years there has been great progress in understanding normal infant development. This work should now be extended to studying high-risk infants. Carefully designed longitudinal studies are essential, notwithstanding their expense and the difficulty of exercising control of experiential variables over time. The effect of the intensive care unit on the size and quality of the mentally retarded population is also a high-priority issue to be elucidated by these longitudinal studies.

Impact on development, behavior, and adjustment of recent trends toward deinstitutionalization, mainstreaming, and normalization. The Bureau of Education for the Handicapped, the Developmental Disabilities Office, and the Office of Child Development (because of Head Start) should also cooperate in this effort.

Studies in this area should include:

- (a) specification of environmental variables influencing community adjustment (public attitudes, welfare legislation, economic conditions, living arrangements) and relation to personal traits (interpersonal skills, work abilities, personality, motivation, intelligence level);
- (b) effect of mainstreaming on self-concept, achievement, out-of-school behavior, preparation for adulthood;
- (c) corollary effect on teacher attitudes, coping skills of teachers, peer acceptance, teaching style, school administration, etc. Also effect of decertification on parental attitudes and relations to the child;
- (d) studies of effect of alternative patterns of care for sub-groups of the retarded; degree of actual community integration; benefits of family or group experience in socialization processes; accessibility and role of community services; significance of administrative support patterns (e.g., privately owned vs. agency-operated group homes);

- (e) assessment of normalization--including definition of "normalizing" incidents; degrees to which differentially handicapped persons are exposed to such opportunities; and the relationship of such varied experiences to behavior and development, as well as their effect on family attitudes, integration into life style, public reaction, and community acceptance.

The mainstreaming and deinstitutionalization movement makes even more urgent the study of outcomes of alternative forms of care. Such studies, when carefully done, are expensive in the short run. They are cheap in terms of long-run societal impact.

Longitudinal lifespan studies of the retarded. These studies are necessary, starting in adolescence, to elucidate the demographic characteristics of the retarded population, about which we know little. This is necessary for basic knowledge and for effective program planning.

Behavior genetics. We know very little about genetic influences on human behavior. Children with subnormal IQ generally end up in institutional settings because of their behavior, not because of their intellectual deficiencies. A number of relatively common disorders, especially those occurring in adults but influenced by factors during childhood, while multifactorial in origin, have a strong genetic component. These conditions include atherosclerosis, diabetes, hypertension, and possibly the major psychoses. A problem of direct relevance to NICHD and NIMH, the so-called XYZ Syndrome, was being studied by competent and scrupulous investigators. Quasi-ethical reasons have caused them to stop increasing their sample size, but longitudinal study of those already in the sample is being continued. Such study of behavioral phenotypes in individuals with specific genotypes, and the analysis of the genotype in individuals with specific behavioral phenotypes, should be supported.

The neurophysiological bases of MR. Studies should be conducted with emphasis on the roles of synaptic conduction, mechanisms for neuronal regeneration and neurocellular pathology.

Prematurity and low birthweight. Research must continue on the mechanism of intrauterine growth and the onset of labor. Ability to prevent high-risk babies is contingent on this knowledge.

Teenage pregnancies. The causes, biological and behavioral, of high-risk pregnancies come together in the teenager. Studies to solve the question of why teenage women become pregnant, not once but often several times, will have great payoff in the effort to prevent MR.

The effects of genetic counseling. Clinical application of genetic knowledge--in the form of counseling and prenatal diagnosis and screening for metabolic and chromosomal disorders as well as conditions that are characterized by morphologic abnormalities--is increasing. We do not have a comprehensive evaluation of its effect upon the consumers. Studies of the motivations, feelings,

attitudes, and experiences of women who have had amniocentesis, including those who underwent elective abortion and those who did not, would be valuable if we are to test the impact of amniocentesis on the emotions and lives of those who experience it.

Autism. This is a field that also needs cooperation with the National Institute of Neurological and Communicative Disorders and Stroke, which now shares the responsibility for it. Autism is a good example of a disorder very close to, but not identical with, MR. Autism is characterized by deficits in intellectual functioning and adaptive behavior; language development is impaired; and some of the symptoms and signs of autism are present in MR-related syndromes. Twenty years ago it was generally seen as psychogenic. Now the presence of an organic component is generally agreed on, although it has yet to be isolated. Interdisciplinary teams should examine longitudinally a group of hard-core autistic youngsters, using neurological, mass spectrometer, and neurophysiological examinations.

Behavior modification. This is an area of intense activity without the benefit of adequate systematic evaluation.

Nutrition. The nutritional basis for MR, including the relationships among maternal malnutrition, teratology, and environmental influences, is still far from clear. Population subgroup diets must also be studied to isolate possible dietary deficiencies. Attitudes toward traditional diets and eating habits should also be investigated.

The connection between mental retardation and delinquency. The epidemiology of the mentally retarded offender must be studied, as well as the role of intelligence in delinquent behavior in children and adults and the question of victimization of the mentally retarded person as the scapegoat.

The impact of the mentally retarded on families and vice versa. This issue provides, perhaps, the perfect bridge between the two Institutes. NIMH has been the center for research on the interaction between children and families. NICHD provides the special emphasis on the mentally retarded. All forms of family care--one-parent, two-parent, foster, substitute, supplementary care--should be researched. In addition to studies that assess the effects of caretaker behavior on the mentally retarded, we need more studies on ways in which characteristics of the mentally retarded affect the flow of interpersonal behavior.

Child abuse and accidents with respect to MR. We do not know whether these phenomena are more or less prevalent among the retarded than among other groups. Although the Office of Child Development has the legislative responsibility for child abuse, it needs the help of NICHD and NIMH to elucidate underlying causes. Without such knowledge, lasting solutions will be impossible. An innovative hypothesis, that should be followed up, is that accidents and child abuse are both reflections of certain stress phenomena, which affect, in particular, those parents without networks of social support.

Development of incentives to encourage development of information programs incorporating the latest research. These information programs are needed for the public (to provide help to troubled families) and for practitioners who treat the retarded. At present there are no incentives either for researchers or health care providers to bridge the gap between them.

The impact of mass media on community attitudes. Our knowledge of media impact on community attitudes toward MR is limited. Public response to propaganda is hard to measure, and only carefully designed field experiments offer hope of adding to our knowledge.

The impact of TV on retarded children. The impact of TV on normal children is assumed to be great, although insufficient research has so far been done. The impact of TV on MR children, by reducing the adult/child interaction, is even more important to evaluate.

Study of social processes with respect to MR. The studies of caretaker groups, institutional and noninstitutional, almost always use the label of caretaker as the independent variable. Theoretically based studies of interactive social processes, which will find variability within caretaking groups, will have much richer payoff.

Study of the borderline areas of MR. Those instances of MR involving no clear physiological basis should be explored in depth (a) to discern mechanisms behind apparent symptoms, (b) to produce classification schemes that relate to probable outcomes of different forms of remediation, (c) to develop testable models for prevention.

The processing mechanisms of MR bureaucracies. Bureaucratic processes should be studied for their own sake within the context of MR treatment programs. These include (a) selection processes for clients; (b) studies of those potential clients who do not come to the attention of the agency; (c) multivariate analysis of social factors, as well as symptoms, which are associated with differential assignment to treatments; (d) the pressures of legal and financial structures in deciding on such assignments; (e) the role of the agency personnel in determining freedom and limitation; (f) the financial consequences of specific decision criteria from the standpoint of the total community as well as that of the specific agency; (g) interagency relationships.

The personality of the mentally retarded. The notion of a relatively fixed personality which is a product of early experiences is increasingly being questioned. Longitudinal studies of mentally retarded persons can add to our knowledge and assess the critical-age hypotheses. The importance of peers in childhood, adolescence, and adulthood is unquestioned. But for mentally retarded persons there seems to be too much emphasis on family or institution or other caretaker and too little attention to the influence of age-mates. The self-concept of the mentally retarded person is an important area; we should

go beyond emphasizing the importance of good self-concept to study realistic self-concepts which lead to realistic levels of aspiration. For the mildly retarded, attempts to discover their perceptions of their social world would help us to establish and evaluate better programs of remediation.

Within-classroom behavior. Research has indicated that teachers use warmth without standards to motivate low-achieving students, with poor educational outcomes. What goes on in the interaction between teacher and student and between student and peers will probably provide better understanding of learning outcomes than will analyses of types of schooling. We do not know enough about within-classroom behavior.

Bioethics. Researchers have no special competence to make ethical decisions. But much research is needed on the impact of ethical decisions before they can be appropriately made. Is intervention always best? Issues include the consequences of life-and-death decisions (complicated by malpractice suits), the long-term economics of severe disabilities, and, for example, what happens to children born with fatal disorders.

Small group research. In view of the move toward the establishment of small, home-like, community living environments for mentally retarded persons, there is merit in research focusing on how small social structures affect mentally retarded persons. What are the outcomes of homogeneous versus heterogeneous (i.e., retarded and nonretarded) group living arrangements or the inclusion of nonretarded, physically disabled persons in a group of mentally retarded persons? How do social structures vary with age and level of mental retardation?

Indicators of social development. In spite of research over the past decade, we still lack adequate indicators of social development. Sustained leadership is essential until this difficult problem is solved.

Resistance to MR in the Community Mental Health Centers. NIMH in particular has a responsibility to study why the mentally retarded have been systematically excluded from CMHC treatment and the effectiveness of steps to include them in the future.

Labeling and stigma. This has already been an area of successful cooperation--including not only NIMH and NICHD, but also Office of Child Development and Bureau of Education for the Handicapped--that resulted in the Hobbs study. This study has left many unanswered questions, however, which should be followed up. Experimental studies of interaction with "labeled" and "unlabeled" mentally retarded persons could provide the information we need on the impact of labeling.

Training for service. Mental retardation and mental health tap into very similar service pools--primary-care personnel, physicians, psychologists, nurses, and social workers. NIMH is the Institute that affects the training of these people. More emphasis is still needed in basic medical training on growth and development in general and mental retardation in particular. This

is necessary in addition to re-introduction of MR into the Community Mental Health Centers programs.

Continuing current research. We support the position of the National Association of Retarded Citizens that priority should be given to completing research already underway. Research within a year or two of completion will benefit today's mentally retarded citizens, and it also contains the seeds of tomorrow's research. Thus, today's research results will in many respects shape our long-term goals. Gaps in funding can mean a loss of one's investments.

APPENDIX

Materials Reviewed by the Consultants

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- Relationships of NICHD and NIMH in the Cultural Deprivation Area (4/15/65)
- Minutes of the meeting of the Staff Group on Mental Retardation held on April 20, 1965 (4/22/65)
- Relationships of NICHD and NIMH in the Cultural Deprivation Area, as endorsed by the Staff Group (6/17/65)
- Relationships of NICHD and NIMH in the Cultural Deprivation Area-- Revised Document Which Staff Group Endorsed at September 20, 1965 meeting (9/24/65)
- Minutes of the Meeting of the Staff Group on Mental Retardation held on November 1, 1965 (11/3/65)
- Growth and Development Program reply to NINDB statement of research grant assignments (10/29/65)

- Guidelines for Assignment of Mental Retardation Applications to NINDB (7/15/65)
- Additional Information Regarding Guidelines for Assignment of Research Grant Applications to NINDB in the Area of the Brain-Damaged Child and Mental Retardation (6/1/65)
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- Research Interests of the Children's Bureau in Mental Retardation (11/29/65)
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Statements of goals and priorities by MRRC directors:

Boston Children's Hospital Medical Center, George Peabody College for Teachers (Nashville, Tenn.), University of Colorado Medical Center (Denver), Albert Einstein College of Medicine (NYC), University of Kansas (Lawrence), University of California at Los Angeles--November 1975; University of Chicago, University of Wisconsin (Madison), University of Washington (Seattle)--December 1975; Children's Hospital Medical Center, Cincinnati, and University of North Carolina (Chapel Hill)--January 1976. None submitted by the twelfth MRRC (Fernald State School, Waltham, Mass.).

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